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ABSTRACT

The paper examines whether a relationship exists between intellectual limitation on the mother's part and unfavorable outcomes for her children. The scope of the problem is examined and the difficulties inherent in estimating prevalence are noted. The issue of child neglect, rather than abuse is shown to be a major problem among institutionalized mentally retarded parents. Studies supporting this problem are cited. Further research indicating that factors other than the mother's intelligence--such as willingness to place the child's needs ahead of her own--may be more important predictors of the mother's ability to improve her child care skills. Additional factors include absence of significant emotional problems and experience in child care. It is suggested that a variety of environmental, medical, economic, and social factors may affect the outcome, with intellectual limitation on the mother's part being additive to other negative environmental influences. Possible intervention approaches include following up children via home visitors, parent skill training, and helping with immediate needs. The paper suggests building in a system of non-coercive supports to existing social, medical, and educational services. Nine recommendations (including screening for literacy by welfare workers and appropriate family planning education in special education programs) are followed by suggestions to medical care or social service personnel for giving instructions, providing more outreach, using family-centered supports for mother and father, and adopting appropriate attitudes. Two final sections address implications for Title V public programs and the role of University Affiliated Facilities. (CL)

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# INTELLECTUALLY LIMITED MOTHERS

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## Introduction

Intellectual limitation on the part of a mother is a risk factor for medical and psychological neglect in her children. The older literature on the subject raised the question of whether mentally retarded individuals should marry and have children. This right is no longer questioned for most mentally retarded people. Therefore, the relevant issue is how to prevent or ameliorate any difficulties experienced by mentally retarded individuals in rearing their children.

A recent review of this topic by Schilling et al. (1982) addresses the question of the correlation between mental retardation in the parent and child maltreatment, and concludes that the literature suggests a relationship. This paper will address the broader question of whether there is a relationship between intellectual limitation on the part of the mother and unfavorable outcome for her children, and, if so, what can be done to improve the mother's effectiveness and mitigate any adverse maternal influences so as to promote normal development for the at risk children. This review will primarily examine the mother's role, since she is the usual focus of intervention, though it is recognized that intellectual limitation on the part of the father also may have biological, economic and/or interactional impact on the children.

The term "intellectual limitation" is used as the preferred one rather than mental retardation, since even reports on deinstitutionalized

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populations include individuals with borderline intelligence. The mothers under discussion are primarily in the mildly retarded category, with fewer being moderately retarded or of borderline intelligence; severely and profoundly retarded people seldom have children and, when they do, they are rarely permitted to be primary caretakers of their offspring. Parental IQ below 50 was found to be associated with predominantly unsatisfactory child care by Mickelson (1947) and Shaw and Wright (1960), while Borgman (1969) found the same to be true of mothers with IQs below 60. Intellectual deficits may impede the successful implementation of tasks involving supervision, interaction and organization. These are significant components of the day-to-day skills required for effective mothering. However, social skills and emotional reactions including displays of affection are equally important, but do not correlate as precisely with intelligence. Information on the relevance of social skills to parenting in intellectually limited mothers is available in only a few of the studies.

Scope of the Problem

The prevalence of intellectually limited mothers can only be estimated based on the prevalence rates of mental retardation and the assumption of a birth rate in this population similar to that of the general population. The widely used prevalence rate for mental retardation is 3%. Newer reports from Scandinavia, using different criteria, suggest a lower rate of around 0.5%. The actual figure for the United States may fall somewhere in between these prevalence rates. Using any of the above estimated prevalences, with at least 75% of the total mentally retarded population in the mild category, the number of at risk mothers is considerable. What makes estimating the prevalence even

more difficult is that some mildly retarded individuals may lead sheltered or protected existences and, therefore, produce fewer offspring. However, one report suggests that the opposite pattern may also be operative. Among the deinstitutionalized mothers they studied, Shaw and Wright (1960) found 50% more live births than the norm for women married at the same age and for the same length of time. Scally (1973) reported that the 4,631 known mentally retarded individuals in Northern Ireland produced 791 births, but offered no data on women in the childbearing age and no comparable data for the general population.

Data on the functioning of intellectually limited women as mothers tend to be based on samples which are unrepresentative of this group as a whole. The deinstitutionalized samples are biased by the fact that institutionalization often resulted from the unavailability of a supportive family or from antisocial behavior, rather than simply mental retardation. The institutionalization itself may have significantly affected the behavior of these individuals. Neglectful and abusive mothers brought to the attention of social or medical agencies, and subsequently found to be intellectually limited, are clearly a group whose parenting skills are deficient. While these two groups may be biased in the direction of poorer social skills, a recent report on intellectually limited mothers of developmentally delayed children (Kaminer et al. 1981) may reflect a favorable bias, since the mothers were successful in negotiating the medical care system and following through on a specialty clinic evaluation of their child. It is, therefore, likely that index cases who come to the attention of medical, social or educational agencies are those in whom difficulties are already identified. Situations in which there are no problems are generally unreported.

The child of an intellectually limited mother may be at a disadvantage in numerous ways. A global measure of the sum of these disadvantages is child neglect. Most studies consider a child neglected only when the evidence is overt and conclusive, though it is acknowledged that lesser degrees of inadequacy in child care may have deleterious emotional and cognitive consequences.

Scally (1973) reviewed the case records of all the retarded persons in Northern Ireland who were married or who were single parents. Of the 720 living children, only 30% were apparently reared satisfactorily in their own homes, while 62% had to have other provisions made for them. The issue of child neglect, rather than abuse, emerges as the dominant problem among mentally retarded parents who had been institutionalized or under state guardianship. Of the 90 families with a mentally retarded parent for whom the state of Minnesota assumed guardianship, Mickelson (1947) found that 42% gave satisfactory care, with the remainder providing questionable or unsatisfatory care. Almost one-third of families in Shaw and Wright's (1960) deinstitutionalized sample from Sheffield were known to have required child protective services. Mattinson (1970) reported on 17 couples where both husband and wife were deinstitutionalized from a hospital in southwest England. Of their 40 living children, 6 had been placed away from the parents by the local authorities. Finally, Floor et al. (1975) report on an American cohort of 54 married couples in which one or both partners had been deinstitutionalized. Only one family had a child removed by the court, and another mother, who was single and thus not part of the above cohort, had placed her children in foster care. However, the length and precise nature of the follow-up procedure was not reported. It must be

understood, when examining the data from these reports, that specific criteria for a judgment of abuse and neglect are usually not spelled out, nor is the basis for the decision for removal from the home. It is possible that a bias against the limited parents may exist on the part of professionals and the courts.

Studies of the intelligence of neglectful mothers have shown a disproportionate number of intellectually limited individuals. Sheridan (1960) tested the intelligence of 100 neglectful mothers and found that 27% were retarded and 43% had borderline intelligence. These women had not been institutionalized; in fact, only 2 had attended special schools. Young (1964) reported that 58 of 110 neglectful parents who had psychometric testing were retarded, while Borgman (1969) noted that, among 50 women referred for psychological testing by child welfare workers, those with IQs below 60 almost invariably provided inadequate mothering.

Using a screening instrument based on history, parental literacy and functioning in a clinic contact, Kaminer et al. (1981) identified 45 families as having at least one intellectually limited parent. This represented 12% of the families presenting to a developmental evaluation clinic, located in an inner city environment, for assessment of their child's developmental delay. One fifth of the children were in foster homes, since the parents had proven unable to care for them.

The intellectual development of the offspring of mentally retarded mothers is a matter of concern for both genetic and environmental reasons. Reed and Anderson (1973) have presented data suggesting that the greater sexual freedom for all members of society may lead to increased numbers of intellectually impaired individuals. It is also

known that women with Down syndrome can reproduce, though the number of reported cases are relatively limited. About 50% of their offspring will inherit the same chromosomal defect.

Intellectually limited mothers are usually poor, may have a suboptimal nutritional status, delayed or inadequate prenatal care, particularly if they cannot negotiate the health care system, and may provide inadequate nutrition, medical care and cognitive stimulation for their children. Scally (1973) found a mean social quotient of 89.6 among the 669 offspring of couples in whom the mean social quotient of the mentally retarded parent was 58.

However, most reports indicate a disproportionate number of mentally retarded children when the parents were mentally retarded. Mickelson noted that, based on school achievement, 23% of the at risk children were mentally retarded. Of the liveborn children in Shaw and Wright's sample, 10.6% were mentally retarded. Three of forty, or 7.5%, of Mattinson's cohort were found to be subnormal. In studying a group of lower class mothers, Heber (1968) found that the 45% of mothers who had IQs below 80 accounted for 78% of the children with IQs below 80.

Intellectually limited individuals face many difficulties in coping with the daily tasks of living in the community. Our individualistic, mobile society offers them few restrictions, but also few supports. For those with limited ability to read, to do arithmetic and to tell time, daily activities such as shopping, traveling on public transportation or keeping medical appointments pose a challenge. All of these tasks are essential to the provision of child care, which also demands an awareness of a child's needs and how they change. Based on clinical experience, many workers have noted that, despite their inadequacies,

intellectually limited mothers are often very committed to their maternal roles. They consider motherhood an achievement worthy of pride, one which enhances their self esteem.

Specific issues that have been identified as problem areas for these parents include organizing a household and carrying out tasks such as cooking and laundry. Standards of physical safety, hygienic care and appropriate behavioral management of children are often unfamiliar to the parents. Awareness of the warning signs of illness such as fever, or the overt manifestations of illness such as seizures, may not be interpreted correctly. Difficulties in negotiating the support systems available in the community, such as welfare offices, hospitals and schools, may preclude obtaining essential services. Planning their time and their children's time and budgeting money may present insurmountable obstacles. Having encountered many failures, these individuals often lack self esteem and do not trust their own judgment. If family supports are unavailable, they may form dependent relationships with people who exloit them.

Some factors appear to be associated with better functioning by the mothers and a more favorable outcome for the children. Investment on the mother's part in her role as a mother and a willingness to place the child's needs ahead of her own have been identified by Rosenberg and McTate (1982) as a more important predictor than is intelligence of the ability of a mother to improve her child care skills. Absence of significant emotional problems on the mother's part is as relevant in this population as it is in the general population. Having had experience in providing child care improves performance. We have observed a mother whose neglect of her children necessitated foster care

placement, but in time she became a competent and caring grandmother. Good health on the child's part makes the mother's task easier. Limiting the size of her family helps to keep the mother from being overwhelmed. Mickelson found that the families providing satisfactory care had an average of 2.5 children, while those providing unsatisfactory care averaged 4.2 children. Good intelligence on the child's part may be a mixed blessing. On the one hand, the child can overcome the effects of understimulation and make good developmental progress; on the other hand, a bright curious child may be too demanding for a limited mother and be perceived as overactive and willful. Often a critical factor affecting the mother's ability to cope is the presence of a benefactor, be it a spouse, a family member or a neighbor, who helps in time of crisis or change and carries out the functions the mother cannot perform. If there is no informal benefactor, this role may be adequately filled by the availability of ongoing help and supervision from a medical or social agency.

There appears to be a complex set of interactions between maternal intellectual deficits and unfavorable outcome for children. Child neglect by the mother and an increased incidence of intellectual deficit in children are the outcomes most often studied. Child abuse is also reported, but is far less prevalent. In this regard, it is noteworthy that Friedrich and Boriskin (1976) reported an association between child abuse and the presence of retardation in the child. However, it was not clear whether preexisting retardation is a causative factor in producing abuse. Therefore, a cause and effect relationship has not been established. It is well known that poverty and intellectual deficits are related; therefore, children of limited mothers are almost

invariably also children of poverty. It would thus appear that a host of environmental, medical, economic and social factors may affect the outcome, with intellectual limitation on the part of the mothers being additive to other negative environmental influences that adversely affect the children at risk.

These interrelationships suggest some possible intervention strategies and therapeutic approaches. For example, mothers of children who fail to thrive without organic cause should be considered for an assessment of their intelligence, since intellectual limitation may be a cause of neglect and the latter can be related to undernutrition and poor weight gain. There is clinical evidence that young pregnant teenagers may be more poorly functioning, both academically and intellectually, and that preventive measures could be usefully targeted at this group. Improved nutrition, easily accessible prenatal care, avoidance of substance abuse and family planning efforts to avoid future pregnancies, form some basic components of a primary prevention strategy among this population.

Intervention Programs

Most professionals would agree that the optimal approach would be primary prevention. However, with the exception of the non-pregnant adolescent identified because of medical or psychosocial problems and for whom family planning is possible, most intervention strategies will have to deal with a limited mother and/or developmentally at risk child, one or both of whom are already experiencing difficulties.

In dealing with early identification of problems with child care, there are lessons to be learned from the British system of providing well child follow-up through the use of home visitors. This approach is

well suited for early identification and provision of assistance to limited mothers who may not access supportive services on their own. It is pertinent that the reported American model programs for helping intellectually limited mothers were not primarily linked to the medical care system, the earliest point of entry into any of the generic service systems for the at risk child.

Project ESPRIT, operated by the ARC in Allegheny County, Pennsylvania, serves 25 families where the primary caretaker is mentally retarded and has an infant under 14 months of age judged to be intellectually normal at birth. Services are provided by home visitors and consist of four one hour direct service units per week and occasional parent meetings. Parents are assessed at regular intervals to evaluate parenting skills, independent living skills and safety in the home. The children's development is assessed regularly and, at age 3 years, the child is placed in a preschool program for normal children. Parent advocacy is provided by the home visitor.

Rosenberg and McTate (1982) reported on their work with 8 mentally retarded parents who were part of the Intensive Services to Families at Risk Project which was supported by the Children's Bureau with assistance from the Administration for Children, Youth and Families. The objective was to prevent the need for foster care of abused and neglected children. Methods used were activity groups focusing on skill learning, problem solving and support. A six week mother-child swim group was also used to improve the quality of interaction. The group was intentionally used to meet the parents' social needs as well as improve skills. Home visits and individual counseling sessions were also employed. Four families required substitute placement for their children.

Based on the UCLA Neuropsychiatric Institute's long range follow-up of mentally retarded adults in the community, Tymchuk (1983) has developed a videotape on counseling retarded couples and a curriculum entitled "Thinking about Marriage and Parenting: Effective Decision Making." His group is currently studying how these parents interact with their children and is training them in parenting skills. The curriculum is designed to assist participants in development of their own plan through the use of a videotape demonstrating interaction styles and a series of illustrated booklets.

The Institute is now working with a new group of five families in 20 weekly sessions involving rigorous evaluation of both parents and children, including father-mother-child interaction evaluations. Parents and children are enrolled in a stimulation project while the parents are also learning adequate parenting and marital styles. The program also includes home visits and transportation for participants.

The common denominator applied in these model intervention efforts for intellectually limited parents has been the provision of some concrete help and advocacy around immediate needs prior to initiating parenting instruction. The parental unmet needs for socialization must also be addressed. Mentally retarded mothers often overgeneralize instructions, form overly dependent relationships and need concrete guidance to recognize changed circumstances which require new strategies. In other words, they may need ongoing monitoring of their functioning with the availability of intervention on an as needed basis.

New Directions

Many changes have occurred in recent decades concerning society's views of the rights of mentally retarded individuals. The elimination

of involuntary sterilization and routine guardianship by the state along with the marked decrease in institutionalization have permitted mentally retarded individuals to exercise their autonomy without restriction or coercive protection. Greater sexual freedom and opportunities for child bearing have also increased the number of mentally retarded individuals in the community who may procreate. However, mentally retarded people continue to have difficulties in coping with various social roles, including an important one such as parenting.

In view of this, it would appear reasonable that a system of non-coercive supports be built into the existing social, medical and educational services which mentally retarded individuals already use. Recognition of an individual's intellectual deficit by service providers is an essential step for connecting her with the additional supportive services.

In order to study the child rearing practices of a more representative sample of intellectually limited mothers than previously described, and to provide services to prevent some of the observed harmful outcomes to children, it is necessary to identify parental limitations prior to evidence of their adverse effects. This raises the sensitive issue of screening and identifying mothers as limited at times when the services they are seeking do not relate to their own educational needs. Any screening device applied in a generic service environment or any other situation creates the problem of potentially stigmatizing the parent. This is counterbalanced by the need for a family based approach to service delivery for at risk parents and their offspring using methods which will improve the outcome for the children while helping the parent to cope. Careful screening, and intelligent

and sensitive management, can achieve necessary identification of cases without unnecessary stigmatization.

A screening instrument, The Einstein Parent Screening Instrument, has been developed by Kaminer, Jedrysek and Soles (1981) to identify at risk mothers (Appendix A). The mothers were considered intellectually limited if documentation of retardation or of marked academic deficiency was obtained by history, or if five of the remaining nine items on the screening scale were present. It has been used in a Developmental Evaluation Clinic and in a primary care setting. It requires further validation in a primary care setting. However, screening women in obstetric and pediatric primary care settings is a useful strategy for identification of maternal intellectual deficit per se, rather than identifying the confounding factors such as previous institutionalization, maternal neglect, or the problems of adapting to a developmentally delayed child. It should also be noted that women suspected of being mentally deficient on the basis of the screening instrument, which focuses on cognitive and coping skills, will require additional confirmation of their level of competence. A social service evaluation and a home visitor to explore skills in areas needed for parenting are required. The ESPRIT project also developed some useful instruments in this regard. Complete psychological testing of the mothers is not usually necessary. The critical area requiring intervention is the adequacy of the mother's parenting skills and not her IQ level.

Recommendations

There are many possible approaches to intervention for intellectually limited mothers and their children. The most reasonable

and practical measures are summarized as follows:

1. Appropriate family planning education in special education programs, preferably including parents of teenagers and with a strong linkage to a family planning clinic.

2. In all family planning clinics where girls under 18 years of age are served, brief screening of academic skills and a request for educational information would help to focus attention on the whole patient and provide useful information concerning intellectual achievement and literacy.

3. Obstetric clinics should provide classes in child care and child development for suspect parents.

4. Screening for intellectual limitation of mothers in pediatric primary care settings, using an instrument such as the Einstein Scale or any other validated instrument.

5. Closer follow-up and specialized management of identified mothers.

6. Screening for literacy by welfare workers.

7. Screening of young children for developmental delay, as is performed with instruments such as the Denver Developmental Screening Test. Children of limited mothers are at greater risk of intellectual deficit, and their development requires close follow-up. If a child is identified as delayed on screening, a careful history to ascertain the parents' educational attainment should be part of the evaluation to determine the etiology of the child's developmental delay.

8. Formal assessment of suspect mothers in order to verify the level of difficulty in adaptive functioning and deficits in parenting skills. Psychometric assessment may be required in some cases.

9. Training of medical, social service and other professional staff to identify and work with this population.

Special Techniques for Working with Intellectually Limited Mothers

The following approaches are recommended in working with families in any medical care or social service setting:

Giving Instructions

(1) Do not take anything for granted (e.g. nose drops go in the nose).

(2) Use demonstrations (e.g. show half a teaspoon).

(3) Use a direct manner (e.g. "you must"; "you have to").

(4) Have the mother perform the task in front of you.

(5) Provide immediate feedback.

(6) Check the same skills on subsequent visits.

(7) Reinforce the mother for indicating when she doesn't understand.

More Outreach

(1) Follow-up calls are needed for each failed appointment.

(2) A professional has to make all contacts with other agencies or else nothing may happen.

Family Centered Supports for Mother (and Father)

(1) Use concrete instruction on housekeeping, child care, dealing with emergencies, use of the telephone.

(2) Provide brief written or pictorial list of frequent activities.

(3) Offer homemaker services.

(4) Provide treatment of children, day care, and after school programs.

(5) Provide telephone number to call for assistance when needed.

Professional Attitudes

(1) Professionals must be attuned to the client's limitations.

(2) Address limitations realistically, but matter of factly.

(3) Understand that parents do not get insulted when a realistic approach to delineating their limitations is made, and appropriate guidance given.

(4) Convey your caring attitude more often and in more concrete ways; use praise for ordinary levels of caregiving or for fulfilling normal expectations.

Implication for Title V Public Programs

The intellectually limited mother with a record of failing to obtain prenatal care, using inappropriate child care practices and offering inadequate supervision of her offspring, presents a challenge to public health officials. There is an increased risk of producing handicapped children in these situations and the mechanisms for providing required services and assuring that the child's needs are met are more difficult to establish and implement. The components of Title V Maternal and Child Health Block Grants that are most pertinent to the management of this problem include: (a) adolescent pregnancy programs where at risk situations can be detected; (b) family planning programs with staff trained to deal with intellectually limited mothers; (c) prenatal care provided with adequate outreach efforts to make services available to these at risk mothers with limited capabilities; (d) early identification made available both in the perinatal and postnatal periods for infant and mother pairs who are in need of special help; and (e) direct services offered to the handicapped or developmentally at risk children. The latter programs must include the capability to offer

parent support, particularly in the prescribed format and in a somewhat less traditional manner than is the usual practice.

Though the scope of the problem is unknown and, therefore, the amount of required special services is uncertain, recent reports indicate that many cases are now undetected and the problem may be a much larger one than was realized in the past.

The Role of University Affiliated Facilities

The role of programs with special expertise in dealing with the intellectually limited mothers and their children is readily apparent. Some of the program models and reports pertaining to this problem have originated from the programs that are part of the national network of University Affiliated Programs for the Developmentally Disabled. Some additional studies and/or projects are needed to clarify the most useful approaches to screening and intervention. One starting point in screening could be the examination of illiterate mothers. Screening instruments need to be validated and larger studies of intervention methods are required in order to demonstrate which approaches yield statistically significant benefits. It would appear that University Affiliated Facilities (UAFs) are an appropriate site for continued research and program development to deal with the problem. In addition, UAFs are the logical vehicles for training of personnel to identify and work with both the mothers and the children. The national network of UAFs can also be used to disseminate program accomplishments and research findings to other centers, as well as to governmental agencies and policy makers who have responsibility for developing new services for those in need.

## Summary and Conclusion

The problem of intellectually limited mothers and their children who are at risk of developmental disabilities is one that is receiving increasing attention. A screening instrument has been developed to identify mothers with potential problems and some model programs for intervention and training have been tested.

While the extent of the problem is uncertain, there is some evidence that children presenting with developmental problems to Developmental Evaluation and Crippled Children's Clinics have a significant chance of being the offspring of an intellectually limited mother. The latter fact may account for some of the difficulties professionals have in being certain that their recommendations are carried out and that future appointments are kept. Abuse and neglect are also significant potential problems, the scope of which are unknown.

It is evident that future studies are required to determine the prevalence of the problem, to establish procedures for proper identification of high risk situations and to validate screening instruments. More model intervention programs are needed along with studies to assess their effectiveness. Though primary prevention is the optimal approach, the major current emphasis will continue to be on secondary prevention. This can be achieved by early identification of mothers in the medical and social agencies with which they are familiar and intervention to mitigate or eliminate the adverse effects of a suboptimal home environment and inadequate child care practices. Effective approaches consist of offering concrete help, support and training to the mothers and providing intervention or stimulation programs to their children.

Appendix A

## CHECKLIST FOR IDENTIFICATION OF INTELLECTUAL LIMITATION IN PARENTS

Ruth Kaminer, M.D.
Eleonora Jedrysek, M.A.
Bee Soles, M.S.W.

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1. Cannot travel alone on public transportation; always comes to clinic accompanied by another adult

2. Reading and writing problems seen when filling out application:

   a. unable to write
   b. writes minimal factual information only
   c. reads words but with very limited comprehension

3. Erratic appointment keeping (early, late, odd excuses, wrong day)

4. Provides vague or naive information about basic facts

5. Problems managing money

6. Overwhelmed by routine demands

7. Child management difficulty of excessive degree observed or reported

8. Uses covering-up techniques to conceal deficit

9. Central role of a "benefactor"; requires help in areas not expected for adult.

10. Historical information documenting limitation/retardation from:

    a. self-report
    b. family member
    c. social agency

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